

Supplemental Information for
Framework for Creating Storytelling Materials to Promote African American/Black Adult
Enrollment in Research on Alzheimer's Disease and Related Disorders

Renã A. S. Robinson¹⁻⁵, Ishan C. Williams⁶, Judy L. Cameron⁷, Keisha Ward⁸, Melissa Knox⁹,
Melita Terry¹⁰, Lisa Tamres⁹, Uchenna Mbawuike⁹, Marita Garrett¹⁰, and Jennifer H. Lingler^{7,9,11*}

¹ *Department of Chemistry, Vanderbilt University, Nashville, TN 37235*

² *Department of Neurology, Vanderbilt University Medical Center, Nashville, TN 37232*

³ *Vanderbilt Memory & Alzheimer's Center, Vanderbilt University Medical Center, Nashville, TN 37212*

⁴ *Vanderbilt Brain Institute, Vanderbilt University Medical Center, Nashville, TN 37232*

⁵ *Vanderbilt Genetics Institute, Vanderbilt University Medical Center, Nashville, TN 37232*

⁶ *School of Nursing, University of Virginia, Charlottesville, VA 22903*

⁷ *Department of Psychiatry, University of Pittsburgh, Pittsburgh, PA 15213*

⁸ *Department of Geriatric Medicine, University of Pittsburgh, Pittsburgh, PA 15219*

⁹ *School of Nursing, University of Pittsburgh, Pittsburgh, PA 15261*

¹⁰ *City of Wilkinsburgh, Partnership for Positive Progress, Pittsburgh, PA 15221*

¹¹ *University of Pittsburgh Alzheimer's Disease Research Center, Pittsburgh, PA 15213*

*Author to whom correspondence should be addressed:

Prof. Jennifer Lingler
School of Nursing
415 Victoria Hall
3500 Victoria Street
Pittsburgh, PA 15261
linglerj@pitt.edu

Supplemental Information

Supplemental Figure S1. Profile material for Annie (.pdf)

Supplemental Figure S2. Q&A material for George

Supplemental Data S1. Long video for Doris (.mp4)

Supplemental Data S2. Short video for Doris (.mp4)

Supplemental Table S1. Example applications of Frameworks recommendations

Supplemental Table 1. Example applications of Frameworks' recommendations

Sample Q&A excerpt	Recommendation applied
<p>"My name is George. I don't have Alzheimer's but I do participate in Alzheimer's disease research."</p>	<p>Find appropriate ways to use past research participants as messengers.</p>
<p>Q: How did you learn about the Alzheimer Disease Research Center? A: "I saw a flyer on the wall that said, 'Do you have forgetful moments?' and 'If you do, would you like to find out if its normal aging or not?' And I laughed: I have plenty of those moments, so perhaps I need to find out."</p>	<p>Acknowledge potential participants' personal experience with or concerns about Alzheimer's.</p>
<p>Q: What was that experience like for you? A: "It was a really good experience. First of all, you go, and you see a social worker and they ask you all kinds of things about your health. And then you see a psychiatrist, the medical doctor—oh, then you take the written part of the assessment, that's the most interesting part. I did good on the memory check, except for one part. Other than that one test, it was a really good experience and I enjoy going every year."</p>	<p>Leverage the positive experiences past research participants have had with the ADRC staff.</p>
<p>Q: What keeps you coming back every year for your visits? A: "Cause I just wanna see what else I can learn. See, did I improve my score? I wanna learn some things that I could do to benefit myself."</p>	<p>Tell stories that emphasize both the "big picture" collective benefits and the personal benefits of participation in the research.</p>
<p>Q: What are your thoughts about the appointment? A: "Going into the appointment, sometimes I feel a little stressed because I feel like I don't want to find out that my memory score was less than it was last time. And there's also one part of this test that I know that I do bad on every time, and I don't think it's going to change. I tell them up front: I say, 'I'm not going to do good on this part,' and the staff says, 'OK, we understand that. If you do the same thing every year on that, we know that that's normal for you.' So, when I come out, I feel that I did the best I could, and there's nothing more I can do."</p>	<p>Avoid "us v. them" perceptions of the researcher/participant relationship by recognizing people's existing knowledge about Alzheimer's.</p>

“I miss my grandmother, she was my sweetheart and I hated it when she got Alzheimer’s.”

Meet Annie.

Annie participates in Alzheimer’s disease research to honor her grandmother.

Annie, age 77, sat down with us to share her story as a research participant at the Alzheimer’s Disease Research Center. Read on to find out more about her motivation to get involved.

Annie spent much of her childhood with her grandmother. She described growing up as “Grandmother’s girl.”

“I stayed with my grandmother off and on until I was about 8. I spent most of my time with her. My mother used to say, ‘You’ve got to come home so you can be raised with the other two,’ because I was the oldest of three siblings. When she said that, I’d say, ‘But Grandmother spoils me!’ Yes, my grandmother was my sweetie, and I was hers.”



Annie explained that, years later, she noticed her grandmother showing signs of having Alzheimer’s disease. Her grandmother would forget all kinds of things, even basic information about the family.

“I remember she even became confused about who was who in our family. One time, she said to me, ‘You’re my daughter,’ without mentioning my mother. Another time, she said, ‘I don’t have a husband. I don’t have any children.’ Alzheimer’s wiped all that out.”



Moved by the eventual loss of her grandmother to the disease, Annie took action by becoming a research participant at the University of Pittsburgh Alzheimer's Disease Research Center.

"When I saw the Alzheimer's Disease Research Center sign, that made me say, 'Well, I better join that because I want to learn more about the disease and figure out if I'm going to get the disease.'"

Annie has been participating in studies at the Alzheimer's Disease Research Center for 13 years and recognizes the importance of her participation.

"I have enjoyed participating in research because it's about learning different things. You hear about so many diseases, and they don't have a cure or full understanding of them. That's why I'm interested in how people develop diseases like Alzheimer's and what researchers are doing to help people."

Annie explained the purpose of research and how it has benefited people who are affected by Alzheimer's.

"The main purpose of the research is to find something to help people. They're trying to find new medications to get on top of diseases like Alzheimer's. I think there is more help for people with Alzheimer's now than when my grandmother had it."

Annie said that even though she'd witnessed the effects of Alzheimer's disease firsthand, she learned even more about Alzheimer's through her participation with the Alzheimer's Disease Research Center.

"I didn't know much about the disease, just what I'd seen in my family. When I saw the flyer for the Alzheimer's study, I signed up right away! I keep coming back so they can use my information as a person who doesn't have the disease. They can then compare me to people who have it and find out how it progresses and where it starts and stops."



Join Annie in becoming a research participant. Participating in research is a rewarding experience!

- Honor a loved one in the fight against Alzheimer's.
- Learn more about how your brain works.
- Feel good about helping others.
- Advance the search for a cure.

Contact the University of Pittsburgh Alzheimer's Disease Research Center to learn more about becoming a research participant at adrc.pitt.edu or 412-692-2700.



University of
Pittsburgh

Alzheimer's Disease Research Center

UPMC Montefiore
421 West
3459 Fifth Avenue
Pittsburgh PA 15213

412-692-2700
adrc.pitt.edu



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